TIIAP FY 1999
Project Narrative

Shepherd Center, Inc

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A. Project Definition

The Need and Target Population. Shepherd Center is a specialty hospital serving people with disabilities resulting from impairments that affect the central nervous system. The Center's services include inpatient acute care and medical rehabilitation. We also operate comprehensive outpatient clinics to address the specialized needs of people with severe disabilities. These clinics address primary health, urology, skin care, vocational services, fitness, and assistive technology (AT), which includes seating and mobility, augmentative communications, computer access, home/worksite accessibility, and adaptive driving.

Among the persons served annually are 350-400 patients who have recently survived a catastrophic brain or spinal cord injury. Less than 60% of these individuals are from communities within 50 mile of the Center. The remainder are from throughout Georgia, the Southeast, and beyond. Many of these patients will be discharged with the need for occasional rehabilitation services (e.g., vocational reentry, assistive technology) and levels of support that can be provided by family or friends. Others will return to their home communities with very complex and often life-threatening support needs. Almost all will face a lifetime of risk for development of secondary conditions, such as pressure ulcers, urinary tract infections, respiratory problems, pain, fatigue, spasticity, depression, and serious psychological impairment. Much of the specialized care provided by Shepherd Center is focused on prevention, treatment, or management of these debilitating complications. But these services are not accessible to all who need them. Because the needs are specialized and affect a relatively small portion of the population, health care professionals in most communities do not have the training or experience to deal with these care needs. Traditional problems with transportation and architectural accessibility also persist. Historically, individuals who needed specialty services had no choice but to travel to the speciality provider ... or to do without.

"Managed care" has also impacted access to needed services. As lengths of stay for rehabilitation have decreased, patients and families simply do not have sufficient time to assimilate all of the knowledge and skills necessary for successful return to the community. During the first weeks after injury most individuals and families have not had time to adjust to the trauma and its consequences. Too often, patients and families leave the hospital feeling emotionally overwhelmed, socially isolated, and educationally unprepared to effectively manage their return to the community. The result has been a steady increase in the prevalence of secondary complications occurring after discharge.

Technology is Part of the Solution. Advanced telecommunications and information technologies have proven useful as a way to bridge the gap between those with specialized care needs living in remote locations and the sources of this specialty care. With the advent of high-speed, high-bandwidth telecommunication networks, telemedicine has emerged as a significant component of the health care delivery system. Telemedicine typically involves linking health care professional to health care professional. Many of these interactions occur between centralized health care settings, which permits the affordable use of high-end, high-bandwidth telecommunications (i.e., the volume may justify the cost). However, much of the need for "telerehabilitation" occurs in home and community (e.g., work) settings, thus limiting the available technology. Less expensive conferencing systems that operate over standard phone lines have been used to support many of these applications.

At Shepherd Center, telerehabilitation has become a valuable tool for extending our reach into the community. Using POTS-based videoconferencing, applications have included prevention and treatment of pressure ulcers, family and patient education and support after discharge, support for the use of assistive technology in home and community settings, and "virtual visits" with family members who live too far away to visit the hospital. We have used telerehabilitation to provide support to patients in remote communities as far away as Mexico or as close as the inner city neighborhoods of south Atlanta. These experiences have taught us that the remoteness of a community may be defined by more than geography--ethnic, cultural, and economic barriers may also prevent access to necessary services (See Appendix B).

Videoconferencing is a useful tool in telerehabilitation but the networking benefits from today's telecommunications technology go far beyond point-to-point communications. The Internet already demonstrates the value of interconnected information resources in business, government, education, and medical applications. Even at the lowest bandwidth connections, standard Internet protocols support extremely valuable data communications. Advanced network capabilities, such as those available with the Next Generation Internet (NGI), will provide significantly greater access to home and community settings. Advanced networks in the not-too-distant future will routinely support voice, video, and data communications throughout the community. NGI technologies provide the bandwidth, security, quality of service, and network management capabilities that are needed to support a telerehabilitation network.

In recognition of this potential, Shepherd Center, Georgia Tech's Biomedical Interactive Technology Center, and MindSpring Enterprises, Inc. propose to develop an NGI network in the metro-Atlanta area linking patients' homes and rehabilitation service providers. This test-bed NGI network will sustain experiments on the leading edge of advanced telecommunications research and, at the same time, serve the practical need for linking off-the-shelf resources. The network will feature a central database in a secure client/server arrangement, using standard Internet protocols to coordinate and distribute remote communications, education, training, and monitoring applications. The database will store and update information about patients and providers. It will store information about equipment configurations at each site in order to facilitate remote network management. This approach also reduces the cost for distribution and maintenance of software because upgrades only need to be made on the server (Appendix B).

Both consumers and providers will access the network, control devices, and exchange information with the central server through a Web browser-based user interface. The program will use advanced browser tools to create an interactive medium for sending data and controlling devices, in addition to traditional browser uses. Communication tools will be developed to integrate network based videoconferencing applications, using a simple user interface that avoids the complex setup and adjustments associated with videoconferencing.

A customized PC-based telecommunications platform will be developed for delivering telerehabilitation applications to patients living in the community. The homes of participating patients will be equipped with the platform and a high-speed network connection for up to 18 months after discharge from inpatient rehabilitation. High bandwidth ADSL or ISDN will support the voice and video applications for remote communications. Encryption and authentication procedures will be used to ensure secure and private access to the network. A home page on the site will be accessible to the general public, but database activities and telerehabilitation applications will be limited to authorized users.

The server database will include disability-specific health and wellness information addressing patients' specialized care needs. This information will be used to deliver, over the network, "just-in-time" interactive, multi-media instruction and support to patients and caregivers. Content will be derived from Shepherd Center's award-winning *Key to Independence* series of print and video materials. Separate versions of the *Key Series* have been published for spinal cord injury (SCI) and traumatic brain injury (TBI), and are also available in English or Spanish translation. The materials provide easy access to essential information about specific health care routines, community resources, and coping skills (See Appendix B).

Discharge protocols for "at-risk" patients and families will be developed, using telerehabilitation to support a successful transition from the hospital back to the home and community. The protocols will specify an appropriate frequency and duration of follow-up telerehabilitation "visits" with the patient and family to provide support and further training, detect potential problems, and provide targeted assistance to reduce or eliminate secondary complications. Protocols will address common problem areas such as pressure ulcers, bowel and bladder management, mobility in the home, and emotional coping and adjustment (See Appendix B).

Measurable Project Outcomes. We believe the proposed work will: 1) improve discharges to the community for newly injured individuals, resulting in fewer secondary complications and re-hospitalizations; and 2) increase patients' and caregivers' participation and self-efficacy in managing patients' care needs, resulting in greater self-esteem and satisfaction with health-related quality of life. Methods for identifying and documenting these outcomes are described in the next section. The long-term impact of this project will be to: 1) demonstrate the utility of advanced telecommunications networks in expanding access to specialized health information and services, and 2) inform health care reimbursement policy decisions concerning the value of technology-based health and wellness services and supports for people with disabilities.

B. Project Evaluation

A formal evaluation will be conducted of the project's effectiveness in helping patients achieve successful community re-entry and avoid secondary complications. The evaluation will examine both clinical and cost-effectiveness of the telerehabilitation network. Dr. Victoria Phillips, health care economist and assistant professor in the Rollins School of Public Health at Emory University, will oversee the evaluation. Dr. Phillips' resume is provided in Appendix D.

Evaluation Questions. Does participation in the telerehabilitation network: 1) reduce secondary complications and rehospitalizations after discharge and, thereby, reduce overall health care costs; and 2) result in greater self-efficacy and satisfaction with health-related quality of life as reported by patients and their families?

Evaluation Methodology. A randomized clinical trial will be conducted wherein 60 recently-injured patients will be recruited to serve in either the experimental (telerehabilitation network) or control (standard discharge) group. The 30 patients in the experimental group will be discharged to the community with access to the network resources and a customized schedule of telerehabilitaiton follow-up visits after discharge. Patient enrollment will occur during the first 4-6 months of the second project year. Patient outcomes will be tracked during regular follow-up interviews conducted by the evaluation team for a minimum of 18 months after discharge.

Data Collection and Measurement. Three primary categories of data will be collected: costs, effectiveness, and cost utility. Total direct costs will be calculated for each participant. These include expenditures for health and rehabilitation services, including any re-hospitalizations or other treatment of secondary complications, and in the case of telerehabilitation applications, the cost of the technology used. Cost data will be derived from review of participant's medical records, intervention records, and interviews with participants, caregivers, and health providers.

Effectiveness will be determined based on the functional status achieved by study participants at follow-up. Outcome measures will include changes in the amount of assistance or supervision required on a daily basis by participants, changes in self-perceived health status (e.g., SF-36), and changes in the degree to which disability interferes with community integration (e.g., Community Integration Questionnaire). Cost utility measures will be calculated based on participants' (or family members') responses on the Quality of Well-Being Scale. Effectiveness and cost utility measures will be collected for all study participants during quarterly telephone interviews with the participant, or a family member or caregiver familiar with the participant's care during the past three months. Phone interviews will be initiated three months after enrollment in the study, and will be made independently from any clinical follow-up calls.

Data Analyses. Time series analysis (using repeated-measures ANOVA) will be used to examine differences in outcomes between the two groups. Standard cost-effectiveness analysis methods recommended by the NIH Panel on Cost-Effectiveness in Health and Medicine will be used. Quality adjusted life years will be calculated based on the average utility rating multiplied by the average life expectancy for each participant, adjusted by age and severity. Results of this analysis will compare the relative cost-effectiveness of telerehabilitation to traditional supports for patients after discharge.

Evaluation Resources. Dr. Phillips will devote a total of 704 hours to the project to conduct the evaluation. A graduate research assistant is also budgeted (1,664 hours) in the last two years to assist with the phone interviews, data entry and analysis. See Table 3 of the Budget Narrative.

C. Project Significance

Innovation. The proposed work complements several existing TIIAP projects that are applying telecommunications and information technologies to deliver health and wellness support to underserved populations in home and community settings. For example, TIIAP grantees are using telemedicine to deliver health services to chronically ill children and older people living in rural Maine. Investigators in Minnesota and Pennsylvania are exploring the use of low-cost videoconferencing and "Web TV" to provide virtual home health visits to older people at risk for chronic illness or disease. TIIAP grantees in Seattle are using information technologies to improve delivery of home care services to low income elderly and disabled individuals.

The work proposed here is distinguished from the efforts noted above in several respects. First, the project represents a strong community partnership between three internationally recognized entities: Shepherd Center, a center of clinical excellence in treatment of catastrophic injury; Georgia Tech, a premier research university in advanced technology and engineering; and MindSpring Enterprises, the country's fastest growing Internet Service Provider. Second, by creating an NGI test-bed in the Atlanta area, the project will be in an ideal position to explore

emerging technologies that may have telemedicine/telerehabilitation applications. Georgia Tech is a development site for the Next Generation Internet and Internet 2. Thus, the project will have immediate access to the latest network technologies. And third, utilizing the clinical expertise provided by Shepherd Center, the project will develop state of the art, interactive information resources available to anyone over the Internet.

Establishing a Model Project. The proposed work is also significant because of the population served. Each year, there are an estimated 60,000 new SCIs and TBIs in the US. Problems with access to specialized services and resources affect people with catastrophic injuries in all communities, so the project has national relevance. As a federally-designated Model System of Care for both SCI and TBI (one of 10 in the country), Shepherd Center is in a unique position to carry out model projects of national significance. This designation as a Model System carries with it the expectation that new approaches and technologies will be developed and disseminated. The flexible network architecture developed in support of this program will be easily extendable to other communities using multiple communications modalities. Additionally, the involvement of major "players" in the telecommunications industry, and the development of resource materials and applications that utilize the Internet should enhance our ability to serve as a resource for people with SCI and TBI, their families, and health providers nationwide.

D. Project Feasibility

Technical Approach. A telerehabilitation network will be established using NGI technologies to deliver secure, high-bandwidth telecommunications to patients' homes. The network will consist of multiple provider stations, multiple patient stations, and a database server. Provider stations will consist of a standard desktop PC with the Intel ProShare videoconferencing utility. Intel supports LAN-based videoconferencing (H.323) through their ProShare product and offers a sophisticated Programmers Developers Kit for integrating ProShare into other applications. Care providers will access the database to retrieve patient information and view physiologic data recorded by the patient at home. "Virtual" visits will allow care providers to monitor patient progress, and provide instruction and support. The use of standards-based videoconferencing (H.323) and data transfer (TCP/IP) will ensure interoperability with other systems and networks.

The patient and provider stations developed for this project will be modifications of the Electronic House Call (EHC) system developed by the BITC in partnership with the Medical College of Georgia and the US Army. Currently in use in the homes of chronically ill patients in Augusta, Georgia, these systems incorporate much of the functionality required for the proposed project. Modifications will be made to incorporate physiologic sensors pertinent to effective management of patients with severe disabilities, to effect secure access to the network, and to enable web browser access to multimedia education tools residing on a server. A detailed description of the EHC system is provided in Appendix B.

Qualifications. The consortium members are uniquely qualified to conduct the research proposed herein due to their past experience and demonstrated success in telerehabilitation, speciality care, advanced telecommunications, and system design, development, and deployment. A description of the strengths of each consortium member is provided in the Partnerships section. Resumes for key personnel participating in the project are provided in appendix D.

Budget and Timeline. A complete budget description is provided in the Budget Narrative. A timeline chart of major project activities and milestones is provided in the appendix. Briefly, the first year of effort will be directed toward establishing the NGI network, modifying the existing EHC platform, and developing multimedia instructional content. The randomized clinical trial will begin early in the second year and continue through the third year. Technical modifications to the telerehabilitation systems and network will be made during years two and three as feedback is received from clinicians and patients. Dissemination of new approaches and evaluation results will begin in year three and continue beyond the initial project period.

Sustainability. One "up-side" to managed care is the increased emphasis on more cost-effective treatment modalities. Funding for telerehabilitation applications is becoming more commonplace as the technology's value is demonstrated. For example, Shepherd Center has been successful in negotiating telerehabilitation follow-up for "at-risk" patients as part of managed care contracts with several commercial funding sources and workers compensation carriers. We also have a model project under way with Georgia's Medicaid agency, the Department of Medical Assitance (DMA), to demonstrate the cost effectiveness of a primary health program for persons with severe disabilities that includes augmenting existing service with telerehabilitation applications. Based on the success of this program, changes to Medicaid funding policies in Georgia that will support use of telerehabilitation for chronic care are being considered.

E. Community Involvement

Partnerships. The proposed project involves a dynamic partnership involving the largest free-standing specialty hospital in the US, a major research university in the fields of telecommunications and information technology, and a corporation on the forefront of technology development and deployment in this area. Shepherd Center will serve as the lead organization for the proposed work and the project will be administered through the Center's Crawford Research Institute (CRI). The Telerehabilitation Program at Shepherd Center is housed within CRI and enjoys the full commitment of Shepherd Center in developing practical home and community–based applications of telecommunication technology. Clinical staff of the Telerehabilitation Program have conducted over 1,000 "visits" with more than 135 patients since the program's inception in 1995.

In 1992, the Georgia Statewide Academic and Medical System (GSAMS), a coordinated distance learning and telemedicine network, was created connecting over 450 sites with high speed (T1) telecommunication lines. The BITC at Georgia Tech was established to develop network and database applications of the telemedicine portion of the GSAMS network. The BITC conducts applied research and development in telemedicine, surgery simulation, rehabilitation, medical imaging, and medical informatics. As part of the Georgia Center for Advanced Telecom-munications Technology, the BITC focuses much of its efforts on the use of advanced telecommunications technologies to enhance the delivery of health care resources.

MindSpring Enterprises, Inc. is a national Internet access provider that focuses on serving individual subscribers, including individuals with little or no prior on-line experience. In addition to ongoing technical support and assistance in disseminating the results of this project, MindSpring will provide the following direct support: 1) server support for the NGI testbed that will house patient records and educational materials; 2) network connections and support

between Shepherd Center, community health providers and 30 patients' homes in the metro-Atlanta area; and 3) technical and financial assistance in preparing multi-media instructional materials and delivering them to patients and providers over the NGI network.

Involvement of the Community. A consumer advisory board will be appointed to ensure consumer input from both rural and urban communities. The board will be recruited from Shepherd Center's 2,000 member peer support network and will include former patients—and their families--who have received assistance through Shepherd Center's Telerehabilitation Program. The board will meet at least annually to review progress on the project and offer their input on its future direction. Community input into the project will also be obtained from the Family Assistance Center (FAC), an organization that coordinates volunteers to support families/caregivers of individuals with brain injuries. The FAC will provide input on the adequacy of support materials and resources for families and caregivers, and will offer assistance in making sure that multi-media instructional materials are appropriate and accessible to targeted users. The FAC will also assist with efforts to disseminate information about the project's effectiveness. Letters of support are provided in Appendix E.

Support for End Users. In Shepherd Center's Telerehabilitation Program, the patient and family are provided with hands-on training in use of the equipment prior to leaving the hospital. This training is aided by using pictographic instructions that go home with the patient and by limiting our applications to equipment that is relatively easy-to-use (similar to installing a VCR). In the proposed project, end user support will be facilitated by: 1) providing patients with an easy-to-use telerehabilitation platform and 2) using the network resources to provide remote support for its use. A graphical user interface will allow patients to easily control the system through voice recognition, touchscreen, or other augmentative communication device pertinent to his/her disability. Help screens with multimedia instructions will guide patients through the use of physiologic measurement devices.

Privacy & Security. One of the reasons the Internet is not widely used to support health care applications is concern over privacy and security. NGI technologies will offer security through encryption algorithms not supported on the current Internet. In addition, data transferred across the network will be encrypted at the application level to assure security over the last mile to the patient terminal. Patient and provider terminals will require secure logins to maintain patient confidentiality. Secure logon at the patient terminal will be accomplished through biometrics (e.g., voice recognition, iris scan, or finger print scan) or an identification card with PIN. Audit trails will be used to record who had access to patient data and when.

F. Reducing Disparities

Certainly geographic, economic, and cultural barriers create disparity in access to specialized health care and to telecommunications resources. However, part of the disparity is a function of who sustains catastrophic injuries and how. Based on statistics from the Model Systems National Databases, 47% of SCI and TBI result from motor vehicle accidents, however 29% are due to violence (primarily gunshot wounds). Violence as an etiology has steadily increased since 1973, when it accounted for less than 5% of all injuries. Those who sustain catastrophic injuries are typically young (average age is 32), male (80%), and unmarried (65%). A small majority (52%) are Caucasian, while African-Americans are significantly over-represented (34%). Less than half (42%) of injury survivors have a high school education. Approximately 30% are un-

insured at the time of injury and, therefore, rely upon public funding (Medicaid/Medicare) or charity for at least part of their medical expenses.

These demographics suggest a target population that probably had limited access to quality health care prior to injury and, therefore, a need for considerable education and support to promote health and wellness after injury. Thus, our focus on continuing supports after discharge and "just-in-time" instruction concerning effective health and wellness activities would appear to be an appropriate response to this need. As for telecommunications access, the Internet offers the ideal medium for providing access to virtually anyone, anywhere, at any time. With time, the NGI should make more advanced applications, such as high-bandwidth videoconferencing, as ubiquitous as today's Internet. By proving the cost-effectiveness of telerehabilitation applications over the NGI, this project will help make this access a reality.

G. Documentation and Dissemination

Documentation Plan. Effective project management will be supported by a plan for documenting and monitoring progress against the proposed project timelines. The Project Timeline presented in the appendix presents major project activities and milestones, staff responsibilities, and approximate dates for completion. Ongoing progress on these activities will be reviewed during monthly meetings among key project staff. Minutes from these meetings will detail progress made and note problems impeding progress. Where problems are noted, corrective actions will be identified including revision of timelines, alternative strategies for accomplishing objectives, or reformulation of objectives. Quarterly progress reports, detailing progress against timelines and project deliverables, will also be prepared and submitted to NTIA.

Dissemination Plan. Our dissemination plan involves using multiple print and electronic media to communicate new knowledge to targeted audiences. Dissemination activities will include: 1) development and delivery of web-based resource and instructional materials; 2) publication of discharge protocols for using telerehabilitation with at-risk patients; 3) technical support and assistance to other rehabilitation providers who wish to establish a telerehabilitation program; and 4) dissemination of program results through presentations at professional meetings and publications in peer-reviewed journals. Web-based instructional materials and discharge protocols will be accessible to anyone over the Internet. Technical assistance will be provided through the Shepherd Telerehabilitation and Resources Training (START) program that was initiated in 1998 in response to the frequency of requests received for assistance in starting telerehabilitation programs (See Appendix B). The project team also has considerable experience with traditional dissemination approaches, as evidenced by the list of Telemedicine and Telerehabilitation Presentations and Publications in Appendix C.

The appropriateness and accessibility of new knowledge will be enhanced by tailoring information (in various media) to the specific learning abilities and preferences of different users, and providing all information in alternative formats, including accommodations for sensory impairment, level of complexity, and alternative languages. Because of the diverse educational and cultural background of the users of this new knowledge, great effort will be taken to convey information in plain language and with ample visual illustrations. In developing web-based information we will follow guidelines set forth by the World Wide Web Consortium's (W3C) Web Accessibility Initiative.